

## Guidelines for a Therapeutic Alliance Between Families and Staff: A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology

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This, the fifth official document of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology, develops another important topic: the Therapeutic Alliance between families and staff. This is addressed to the Pediatric Oncology Community as Guidelines that could be followed. Every parent, medical staff member, and psychosocial professional in-

involved in the care of the child should be responsible for cooperating in the child's best interest. Everyone must work together toward the common goal of curing the cancer and minimizing its medical and psychosocial side-effects. *Med. Pediatr. Oncol.* 30:183–186, 1998 © 1998 Wiley-Liss, Inc.

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### INTRODUCTION

The diagnosis of a malignant disease in a child produces sudden and overwhelming challenges for the family. An initial phase of fear, shock and disbelief is common, often followed by complex and contradictory reactions. A debilitating paralysis or isolation can result from the anxiety and stress. Most primary coping patterns involve the mobilization of intense energy.

Depending upon personalities and circumstances, these energies can express themselves in various ways.

On one hand, there may be denial, anger and belligerence; on another, passivity and withdrawal. On still another, a compulsion to learn more about the disease and its treatment, a need to deal positively with friends and family, a need to do everything possible for the child and a wish to collaborate actively in medical care. Often these styles coexist interchangeably over time, and are displayed differently by family members.

Even for health care workers, especially doctors and nurses, there is a great emotional investment involved in dealing with children with cancer. Often, however, such

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energies are dispersed and weakened by the need to resolve bureaucratic problems, assert their standing as experts, deal with a lack of resources, and respond to family members' misunderstandings, fears and distrust regarding the treatment and prognosis of their ill child.

The will of parents, child, other family members and friends to fight the disease, together with the staff, expresses itself in each country, and in each economic class, through different social and cultural patterns. In many nations and medical centers, parent-family and volunteer associations have formed to help one another and the medical staff in this work. These associations are uplifting examples of the expression of collective caring, energy and solidarity.

### Therapeutic Alliances

Wasteful expenditure of negative energy by anyone involved might be more profitably used, and in turn mobilize new and even more powerful positive energies, by cooperating toward fighting the disease in a therapeutic alliance. This alliance may take one or both of two forms: (1) an alliance between individual family members—parents and children— and individual medical staff members; and (2) an alliance between families as a group and health care team members as a group. These therapeutic alliances are formed when both parties work together with a common purpose pooling resources toward a common goal: curing the cancer and minimizing its medical and psychosocial side-effects, and mobilizing the energies of all members of the Society to this end (Fig.).

In the following portion of this document we list recommendations derived from experience in various countries and various socio-cultural settings. This working committee recommends these guidelines as components directed toward the realization of an alliance in each medical center between individual family members and individual members of the health care team and between families as a group and members of the health care team as a group. We believe that every parent, and medical or psychosocial professional involved in the care of the child to be responsible for cooperating in the child's best interest. Since treatment goals and procedures change during and after the course of treatment, the role and importance of any individual involved in this alliance will also change over time.

The SIOP Psychosocial Committee in related documents has expressed the general theme of family-staff cooperation [1–4]. The alliances we focus on emphasize the two-way nature of this cooperative partnership in the delivery of health care to the child with cancer. Each party—child, parents and health care staff—have particular obligations and responsibilities in this relationship. Included among them are the staff's obligation to provide the best available scientifically established care and the child's rightful expectation to receive that care. The child

and parents have the obligation to seek fulfillment of their personal needs and the staff has the obligation to suggest and argue for necessary medical or psychosocial programs. A mutual responsibility is to recognize and respect the specific and often different skills and expertise of family members and staff members. The staff, for example, are expert in the disease and its treatment, while parents and children are unquestioned experts insofar as their unique nature and needs/preferences are concerned.

### The Relationship Between Individual Family Members and Staff Members

The role of physicians and health care team members is to:

1. Treat one another (physicians, residents, nurses, psychologists, social workers, health educators, etc.) with respect for their different professional expertise and interests.
2. Treat parents and children with respect in acknowledgement of their unique value systems and skills.
3. Ask parents and children about their preferences and needs for psychosocial care.
4. Educate parents and children about the nature of the diagnosis and treatment, and involve them as appropriate in critical decisions regarding treatment.
5. Ensure that other family members understand the diagnosis and treatment.
6. Help parents deal with the negative aspects of medical bureaucratization.
7. Have regular (weekly if possible) staff meetings attended by physicians, nurses and psychosocial staff to discuss the psychosocial problems of children and families so as to improve the contact. Try to discuss in these psychosocial case reviews the relationships of staff members to the family members.
8. Give the individual child/patient/young adult the guidance and support needed to regain and establish his/her personal autonomy after the setbacks and restrictions that occur during treatment of childhood cancer.

The role of family members is to:

1. Ensure that free communication exists between the child, parents and other family members.
2. Seek information from the staff.
3. Treat the staff with due respect for their expertise and skills (neither resulting in dependency nor complete autonomy).
4. Provide relevant information for medical and psychosocial intervention.

### The Relationship between Families as a Group and the Health Care Team as a Group

The role of physicians and health care team members is to:

1. Dedicate time, energy and creativity to collaborate

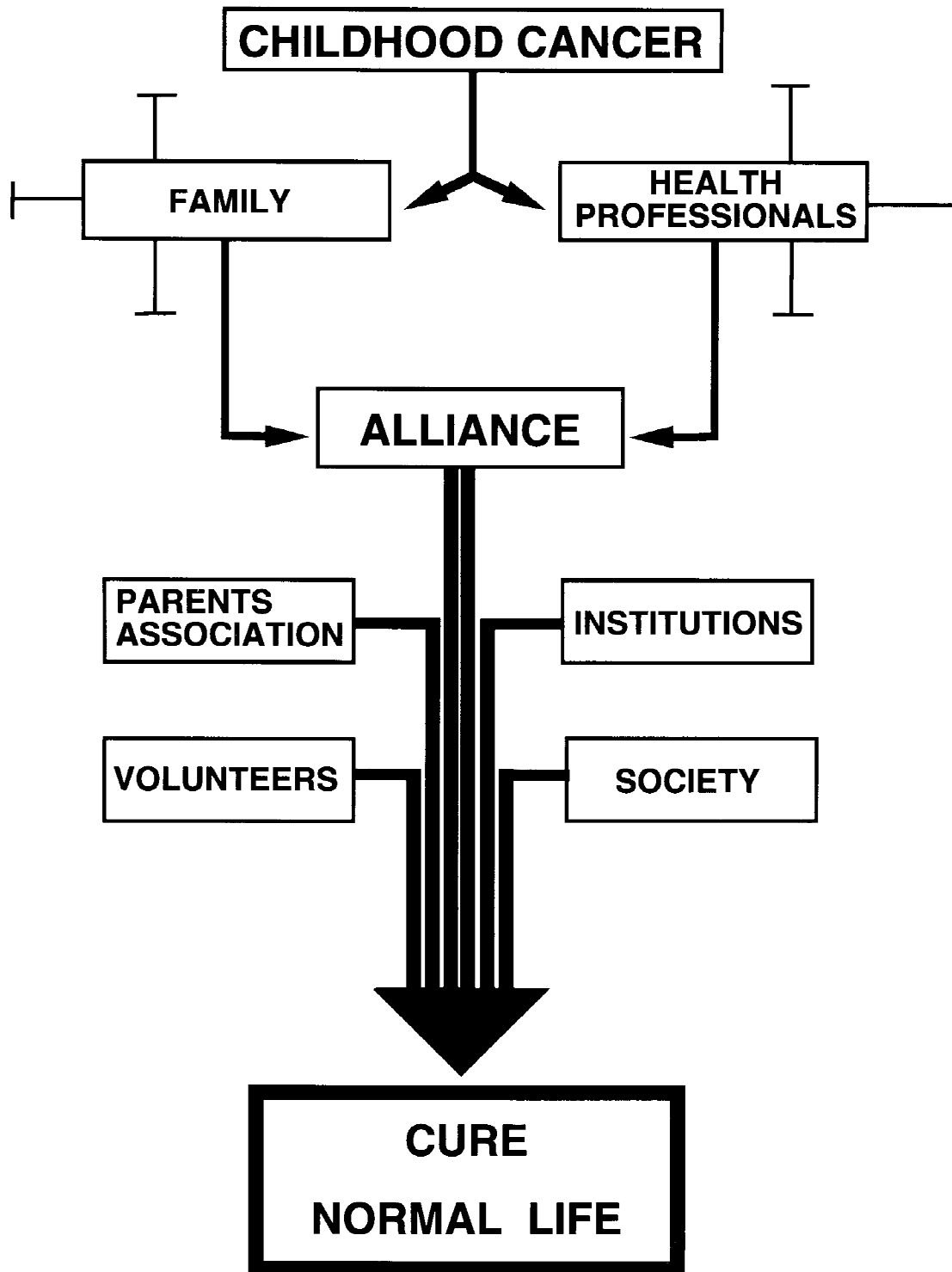


Fig. 1.

with parent associations by suggesting and arranging joint meetings and acting in advisory capacities.

2. Encourage all parents, especially shy or cautious parents, to join a parent association and help activate parents to organize such associations where they do not already exist.

3. Have parent association members, together with members of the health care team, cooperate in deciding upon a global medical, psychosocial and social-cultural intervention program, toward which they all can converge their united energies.

4. Do all in their power to ensure that cured children

and young adults are successfully reintegrated into society, without being penalized in school, work, social relations or insurability for having had cancer as a child.

The role of families is to:

1. Work with the staff to ensure that children with cancer receive not only medical care but a total intervention that includes psychosocial, educational, social and economic care as well.

2. Collaborate with members of the health care team to help resolve issues in support, treatment and research.

3. Take the initiative in suggesting and arranging joint meetings with health care team members, community volunteers, hospital/clinic officials and members of the community at large.

4. Attend carefully to the need for children and young adults to form their own associations, based upon their unique rights, responsibilities and requirements.

5. Become aware of their obligations and responsibilities, and the roles they can fill, as members of parent associations, both within the medical care system and in the effort to mobilize energies of every stratum of society (extended family members, volunteers, friends, the general public, health care and governmental authorities) to improve the care of children with cancer.

6. Organize parent associations at various levels:

- a. **Locally**, within the hospital where the child is undergoing treatment. Medical staff members should be requested to act as advisers and consultants regarding clarification of strategies of medical or social intervention. The parents, without exception, should be the ones responsible for direction of the association itself and for gathering and dispersing economic and other resources. Where family and community energy and resources are poor, health team members can help in the process of organization and provide temporary leadership and advice. It is important that parents association have frequent meetings, activate and support self-help activities, and communicate with all parents through some sort of newsletter.

- b. **Nationally and Internationally**: the objective should be to increase the awareness of institutional structures, governmental bodies, and public opinion to issues in pediatric oncology, through written and video media. Many national organizations of parent associations and the International Confederation of Childhood Cancer Parent Organizations (ICCCPO)\* are dedicated to such efforts.

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